Completion of Advanced Care Directives Is Associated with Willingness to Donate

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Objectives: A useful framework for initiating organ donation discussions in the primary care setting may help increase willingness to donate and thereby increase the frequency of organ transplantation. Given the lower willingness to donate among African Americans and that a higher proportion of African Americans die while waiting for an organ transplant, this is an important group to consider in such an approach. We examined the association among completion of a living will and willingness to donate and the influence of race in this relationship.

Methods: A nationwide telephone interview survey using random digit dialing of households in high- and low-density African-American census blocks.

Results: One hundred-eighty-eight adults participated (41% cooperation rate). In a multivariate model, factors associated with willingness to donate included having signed a living will (OR=2.43, 95% CI=1.13–5.23), talking with a physician about organ donation (OR=3.04, 95% CI=1.07–8.67) and white race (OR=2.5, 95% CI=1.23–5).

Conclusion: The public is generally supportive of organ donation although African Americans remain less willing to donate after controlling for confounding variables. Physicians interested in increasing donation rates should consider incorporating organ donation into discussions of advance care planning and end-of-life care.

Key words: race/ethnicity ■ advanced directives ■ organ donation ■ primary care

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INTRODUCTION

National organ donation rates remain extremely low despite numerous attempts to improve them. Transplantation issues disproportionately affect African Americans who comprise only 12% of the U.S. population yet make up over one-quarter of the 89,000 persons on the waiting list for organs and over one-half of those waiting for donated kidneys.[1,2] At the same time, several studies have shown that African Americans are less willing to donate than whites.[3,4] While many of the barriers and facilitators to donation among African Americans have been identified,[3,5,6] a useful framework for discussing and encouraging organ donation in this population continues to be sought.

The ambulatory setting may be a good location to broach organ donation. First, 35% of deceased organ donors are age >50, the same group that has the highest frequency of ambulatory visits in the United States.[7] Second, the patient's primary care physician, who may have a strong rapport with the patient and may have established some degree of patient trust, can initiate the discussion. In addition, the physician may be able to impart knowledge and understanding of the donation and allocation process[8] while dispelling the myths and inaccuracies that have been found to inhibit willingness to donate.[5] Third, the subject of organ donation has close ties with that of end-of-life care, as the majority of donations occur following death. Studies generally support the use of the ambulatory setting to discuss advance care planning, including advanced directives such as living wills.[9,10] In 2002, the Joint Commission on Accreditation of Healthcare Organizations revised its hospital standards to require that hospital-based ambulatory clinics be equipped to assist patients with advanced directives. This is supported by the fact that patients asked about advanced directives by their physicians are three times more likely to complete a living will than those who had never been asked.[11] Linking discussions of organ donation to those of advanced directives in the ambulatory setting may increase willingness to donate while allowing patients autonomy, altruism and shared deci-

sion-making at the end of life.

Although it has been demonstrated that discussing end-of-life care with family members is associated with an increased willingness to donate,[12] to our knowledge, no study has examined the association between considering end-of-life issues through the use of advanced directives and willingness to donate and whether such a strategy might help minimize the discrepancy of lower African-American donation rates. This might be especially effective in reaching communities such as African Americans, where media-based donation campaigns have been less successful in increasing donation rates. An association between completion of living wills and willingness to donate would suggest an opportunity to increase awareness, understanding and receptivity toward organ donation by including a brief discussion of this issue during advance care planning discussions. Therefore, we identified a randomly selected nationwide sample of adults in high- and low-density African-American-populated census blocks to examine the associations among race, presence of a living will, talking with a physician regarding donation and personal willingness to donate. We then identified factors that were predictive of having a living will and of willingness to donate among this cohort.

METHODS

Study Participants

Study participants were recruited using random-digit dialing by the Social and Economic Sciences Research Center at Washington State University. For this survey, all adults nationwide were considered eligible to participate. However, since African-American households were of particular interest, households listed in Census block definitions with ≥1 African-American resident defined the population. Using this definition, the eligible study population included approximately 13 million out of 105.5 million U.S. households, as African Americans represent 12.7% of the U.S. population.[2]

Genesys Sampling (Fort Washington, PA) provided 1,949 random numbers for the goal of 150 completed interviews. Genesys generated two separate telephone lists. The first list consisted of 1,336 randomly generated nationwide telephone numbers in which area code and prefix combinations produced ≥80% incidence of African-American households. The second list contained 613 numbers generated from area code and prefix combinations associated with blocks having ≥1 African-American household and up to 79% incidence of African-American

Table 1. Descriptive statistics

	All*	African Americans	Whites	P Value
	180	98 (59%)	69 (41%)	
Age (Years), mean ± SD	39.6 ± 14.4	36.0 ± 14.1	45.4 ± 15.4	0.02
Women	116 (64%)	70 (71%)	39 (56%)	0.05
Ethnicity				
African-American	98 (56%)			
White	69 (39%)			
Other	8 (5%)			
Religion				<0.001
None	17 (10%)	5 (5%)	12 (18%)	
Baptist	53 (31%)	36 (38%)	11 (16%)	
Catholic	23 (13%)	6 (7%)	15 (22%)	
Methodist	10 (6%)	2 (2%)	7 (11%)	
Presbyterian	7 (4%)	1 (1%)	5 (8%)	
Other	63 (36%)	44 (47%)	17 (25%)	
Married	86 (51%)	36 (38%)	45 (71%)	<0.001
Number of Children, mean ± SD	2.0 ± 1.7	2.0 ±1.8	2.1 ± 1.5	0.58
Education				0.97
No high school	12 (7%)	6 (6%)	3 (4%)	
High school	41 (23%)	19 (19%)	19 (28%)	
Some college	51 (29%)	32 (33%)	16 (24%)	
College	52 (29%)	30 (31%)	20 (29%)	
Graduate school	22 (12%)	11 (11%)	10 (155)	
Employment Status				0.22
Employed	13 (7%)	9 (9%)	2 (3%)	
Retired	44 (25%)	22 (23%)	19 (28%)	
Unemployed	113 (63%)	64 (66%)	44 (64%)	
Student	8 (5%)	2 (2%)	4 (6%)	

* Totals for all participants are greater than the sum of African-American and white participants as race was not available for some individuals.

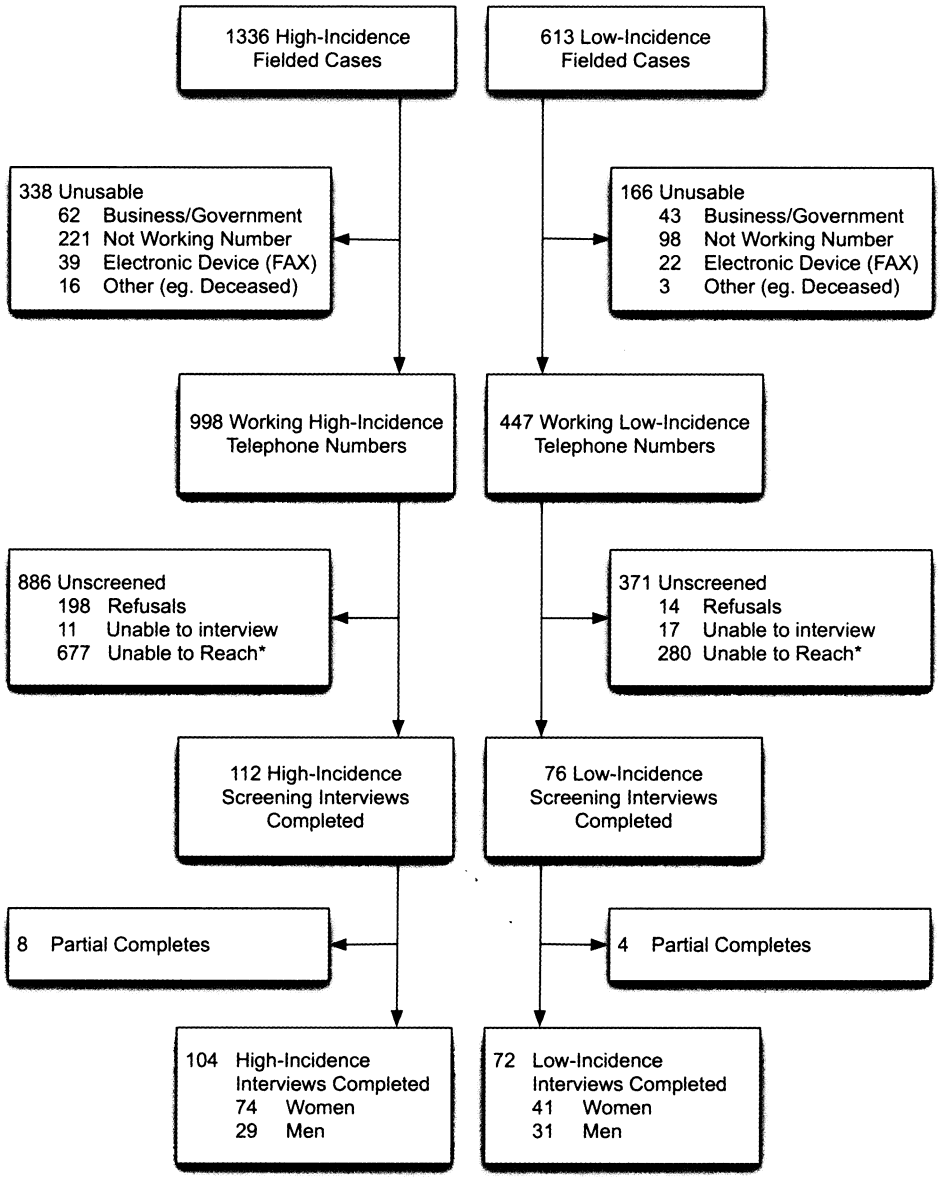
households. The ≤79% incidence of African-American households list was included to ensure coverage of African Americans in low-incidence areas who may differ from those of high-incidence areas in use of living wills and willingness to donate. From the first list of 1,336 high-density numbers, Genesys was able to match residential mailing address information to 799 (41%) of the cases. From the second list of 613 lower-density numbers, 376 (61%) were matched back to mailing addresses.

In order to maximize response rates, we sent presurvey letters to potential participants whose addresses we identified describing the study and apprising them that an interviewer would be calling soon to conduct the interview. The letter also provided the respondent with the option of completing the survey anonymously and securely via the World Wide Web. A randomly assigned password was provided in the letter.

From the total of 1,336 high-density and 613 low-density telephone numbers provided, 998 high-density and 447 low-density working residential phone numbers were identified (Figure 1). Interviewers completed a "screening" interview with an English-speaking adult at the household whose birthday was closest to the interview date. Homes that were not successfully contacted on the first attempt were dialed up to eight additional times at different times during the day. A total of 183 persons completed the survey—176 via phone and seven via the web.

Cooperation and minimum response rates were calculated according to the criteria stipulated by The American Association of Public Research.[13] In calculating the cooperation rate, only known eligible households who were contacted were used in the denominator. One-hundred-seventy-six phone surveys were completed and 12 partially completed of 460 eligible homes (272 refusals, 12 partial completes and 176 completed interviews)—a cooperation rate of 41% among individuals known to be eligible. The minimum response rate attempts to take into account the total number of eligible households who were or were not contacted. This estimate is the proportion of completed and partially completed interviews (in our case, 188) of total households contacted, including refusals (272), those unable to be reached or interviewed (985), and completed and par-

Figure 1. Survey sample



* A minimum of eight call attempts at different times of the day was made for all unable to reach numbers

tial interviews (188). Our minimum response rate was 13%. The cooperation and minimal response rates were slightly conservative estimates as they did not include the seven completed web surveys.

Survey Administration

In order to ensure nonbiased, uniform and accurate survey administration, the 25 survey administrators received 10 hours of training and one hour of practice using *Interviewer* computer-assisted telephone interviewing system (CATI) software (Voxco Corp., Montreal) prior to calling and using the actual survey. At all times during the course of training and project calling, ≥1 supervisors were available to provide quality control and to respond to interviewers' needs and questions. In addition, 17 phone interviews were directly monitored in their entirety to minimize interviewer effect.

The questionnaire and CATI system were pilot-tested on a convenience sample of six participants and revised accordingly before broad distribution. The institutional review boards at the University of Washington and Washington State University approved this project.

Survey Description

Assessment of willingness to donate organs. Respondents were asked whether they supported organ donation and if they had signed an organ donor card. Those who responded that they had not signed a card but supported donation were then asked how soon they anticipated signing a donor card, in an effort to gauge the likelihood of turning intention into action. Respondents' willingness to donate organs was then assessed by asking them, "How likely are you to have your organs donated after your death?" Four possible ordinal responses were used to measure the respondent's current stage in the decision-making process as an adaptation of the Transtheoretical Model of Health Behavior Change.[14,15] Choices included "not at all likely" (unwilling), "not very likely" (precontemplative), "somewhat likely" (contemplative), and "very likely" (preparation). "I don't know" was also an option. Responses were analyzed as a four-point ordinal scale and also a dichotomous scale by considering "very likely" in a category considered likely to donate and "somewhat likely", "not very likely" and "not at all likely" in a category considered unlikely to donate. To elicit whether participants had discussed these decisions with others, this question was followed by:

1. "Have you told your family?"
2. "Have you told your friends?"
3. "Have you told your physician?"

Willingness for living kidney donation was assessed by asking if respondents were willing to donate a kidney to a family member.

Assessment of End-of-Life Considerations

Respondents were asked whether they had considered end-of-life issues. Examined factors included those that may be considered in the context of end-of-life issues, including caring for a loved one who passed away, having signed a living will and talking with a physician regarding end-of-life issues. For each of these items, respondents could respond "yes," "no" or "I don't know." Respondents were also asked to rate their health status on a five-point ordinal scale from "poor" to "excellent," and whether they had ever spent the night in a hospital.

Characterization of Ethnicity, Gender and Other Demographic Factors

Information was collected from respondents on age, ethnicity, gender, city of residence, religious preference, level of education obtained, employment

Table 2. Health status of participants

	All*	African Americans	Whites	P Value
	n (%)	n (%)	n (%)	
Health Status				0.48
Poor	8 (4%)	4 (4%)	4 (6%)	
Fair	19 (11%)	13 (13%)	4 (6%)	
Good	42 (24%)	24 (25%)	17 (25%)	
Very good	63 (35%)	33 (34%)	24 (35%)	
Excellent	42 (26%)	24 (24%)	19 (28%)	
Overnight Stay in Hospital	131 (73%)	70 (71%)	54 (78%)	0.32
Participated in Care of Family Who Died	83 (46%)	38 (39%)	38 (55%)	0.04
Have a Personal Living Will	65 (36%)	29 (30%)	31 (45%)	0.04
Discussed End of Life with MD	25 (14%)	11 (11%)	11 (16%)	0.37

* Totals for all participants are greater than the sum of African-American and white participants as race was not available for some individuals.

status and marital status. Self-reported race and ethnicity was recorded as recommended in recent studies.[16,17] Respondents were asked about their ethnicity and offered 11 possible selections, including "other," which allowed them to state another option. Respondents were encouraged to select as many options as they felt reflected their ethnicity, and could choose from among eight different religions practiced, including "other" and "no religion."

Statistical Analysis

The goal of our analyses was to identify predictors of signing a living will and predictors of willingness to donate. Signing a living will is a dichotomous variable, so Chi-squared analysis was used for comparing categorical predictor variables, Chi-squared test for trend was used for comparing ordinal predictor variables, and Student's t test was used to compare means of continuous predictor variables. Willingness to donate is an ordinal variable, so we used Chi square for trend for dichotomous predictor variables and ANOVA for ordinal and continuous predictor variables. Covariates with a statistically significant relationship ($P<0.05$) to the outcomes of interest were included in the multivariate linear and logistic regression analyses. The outcome variable of willingness to donate was modeled as an ordinal variable reflecting increasing willingness to donate ranging from "not at all likely to have organs donated after death" to "very likely to have organs donated after death," as described previously. Ordinal logistic regression was used to assess the prevalence and strength of relationship between willingness to donate as the ordinal outcome variable and having signed a living will as the predictor variable. Ordinal logistic regression was also used to assess whether the association between willingness to donate and having signed a living will persisted after controlling for potential confounding variables, including gender, race, discussing organ donation with a primary physician and willingness to receive a transplant if needed. These covariates were chosen based on their hypothesized association with the outcome variable and their association with willingness to donate in the univariate analysis. The approximate test of the proportional odds assumption was used to ensure that the ratio of cumulative odds for categories of willingness to donate was constant.[18] The same model was also analyzed using logistic regression with willingness to donate as a binary outcome variable. This served as a confirmatory analysis of the ordinal logistic regression model. Similarly, predictors of having signed a living will were also analyzed using logistic regression. All analyses were conducted using Stata/SE 7.0 Software (STATA Corp., College Station, TX).

RESULTS

Respondent Characteristics

The descriptive characteristics of the cohort can be found in Table 1. As expected, given our sampling strategy, African Americans were the predominant ethnic group. Ages ranged from 17–75 with a mean ± SD age of 39.6 ± 14.4. African Americans were younger than whites ($P=0.02$). Women comprised 64% of the cohort and represented a larger proportion of African Americans compared to whites ($P=0.05$). A higher percentage of African-American respondents compared to white respondents identified themselves as Christian ($P<0.001$), but a fewer

Table 3. Willingness to become an organ donator

	All*	African Americans	Whites	P Value
	n (%)	n (%)	n (%)	
Support the Concept of Donation	164 (93%)	87 (92%)	65 (96%)	0.31
Willing to Donate Organs after Death				0.027
Very likely	84 (48%)	38 (40%)	42 (63%)	
Somewhat likely	48 (28%)	32 (33%)	11 (16%)	
Not very likely	16 (9%)	10 (10%)	5 (8%)	
Not at all likely	27 (15%)	16 (17%)	9 (13%)	
Have a Driver's License	162 (90%)	86 (88%)	65 (94%)	0.16
Signed a Donor Card	58 (70%)	25 (66%)	30 (73%)	0.48
Have Told Family about Decision to Donate or Not Donate	86 (48%)	36 (37%)	45 (66%)	<0.001
Have Told Friends about Decision to Donate or Not Donate	49 (27%)	24 (24%)	22 (32%)	0.29
Have Told Primary Physician about Decision to Donate or Not Donate	34 (19%)	18 (19%)	13 (19%)	0.89
Would Donate Kidney to Family Member	163 (94%)	85 (91%)	65 (98%)	0.06
Would Want to Receive a Transplant if Needed	146 (88%)	80 (90%)	55 (86%)	0.45

* Totals for all participants are greater than the sum of African American and white participants as race was not available for some individuals.

proportion were married (P<0.001). There was no difference between African Americans and whites in education level or employment status.

Self-reported health status was similar between men and women and between African Americans and whites (Table 2). There was no statistically significant difference between the proportion of African Americans and whites that had spent ≥1 night in the hospital (P=0.32). More whites had participated in the care of a family member who had died (P=0.04) and had signed a living will (P=0.04) compared to African Americans. However, there was no difference between whites and African Americans in having discussed end-of-life care with a physician. Overall, only 14% or 25 persons of the entire cohort had discussed end-of-life care with a physician.

Willingness to Donate Organs and Talking with Others about Donation

There was a high level of support for the concept of organ donation among the entire cohort (93%) with no differences between African Americans and whites (Table 3). There was no difference between the percentage of African Americans and whites who had obtained a driver's license or who had signed an organ donor card. However, African Americans were less willing than whites to sign a donor card (P=0.027). Although not significant, there was a trend towards white respondents being more willing to provide a living kidney donation to a family member (98% compared to 91%, P=0.06). African Americans and whites were equally willing to receive a transplant if necessary. Whites were much more likely than African Americans to have spoken with family regarding their donation decision (P<0.001), but there was no significant difference between African Americans and whites with regard to talking about donation with friends or their primary physician.

Living Will Predictors

Adjustment for significant respondent characteristics in a multivariate logistic regression model using presence of a living will as the binary outcome variable identified the following significant predictors of having a living will, after controlling for potential confounding variables: increasing level of education, having talked with a physician regarding end-of-life issues, and having previously spent ≥1 night in the hospital (Table 4). Race or ethnicity was not found to be a significant independent predictor of having signed a living will in this model (P=0.1) despite being significant in the bivariate analysis (P=0.04). Gender, while not significant at the P<0.05 level, was retained in the model as it might be a significant confounding variable with regard to race and ethnicity.

Table 4. Predictors of presence of living will

Predictor Variables	OR	(95% CI)
Female gender	0.82	(0.37–1.80)
African-American race	0.53	(0.25–1.13)
Increasing level of education	1.46	(1.02–2.07)
Having discussed end-of-life issues with a physician	16.1	(4.28–60.5)
Having spent ≥1 night in the hospital	3.34	(1.29–8.64)

Willingness to Donate Predictors

Table 5 displays the results of the adjusted multivariate ordinal logistic regression model using willingness to donate as the ordinal outcome variable. The following significant predictors of willingness to donate were identified after controlling for potential confounding variables: white compared to African-American race, presence of a living will, talking about organ donation with a physician and willingness to receive a transplant if necessary. Gender was not found to be significant in this model but was retained to adjust for the variable's potentially confounding effects on the relationship race and willingness to donate. Similar results were obtained using a standard logistic regression model.

DISCUSSION

In this population-based study, we found that race is associated with the presence of a living will and willingness to become an organ donor. One of the biggest predictors of having a living will in this cohort was having talked with a physician regarding end-of-life issues. Among both African Americans and whites, the presence of a living will and talking about organ donation with a physician were highly associated with willingness to donate. This study suggests the important potential value of physicians in helping their patients understand and plan for these two important areas of end-of-life care. Our findings suggest that routine incorporation of organ donation into the discussion of end-of-life care by primary care physicians might lead to an increased willingness to become an organ donor and should be tested in future studies.

While the role of primary care physicians in end-of-life care has been well established and encouraged,[9,10,19] little is known about the role primary care physicians play in the organ donation process. Many studies have detailed the role of physicians in discussing end-of-life and organ donation with patients and their families in the intensive care unit.[8,20] However, this is an acute situation following a major medical event. The intensive care unit may not be the ideal place for physician–patient discussions regarding organ donation. First, such discussions often take place in the absence of the patient, as they may be too

ill to communicate their wishes. Surrogate caregivers who may have the legal power to speak on the patient's behalf may or may not know or honor the patient's wishes. Second, physicians may find the majority of their time and energy consumed with guiding the patient's family through medical decision-making for the patient and the grieving process and not feel ready or able to initiate discussions regarding organ donation. In a recent study, one-third of intensivists did not believe it was their role to request organ donation.[21] This is important to note as Siminoff et al. found attitudes regarding donation among healthcare providers to be a bigger barrier than providers' knowledge level in successful organ retrieval.[22]

Currently in the ambulatory setting, few primary care physicians are directly involved in the donation process, suggesting an opportunity for intervention. In one study, 69% of primary care physicians had never discussed organ donation with their patients during routine office visits.[23] A randomized, controlled trial comparing use of brief verbal discussions and written materials to written materials alone during routine family practice office visits among patients who had not previously consent to become organ donors found no difference in the proportion in each group who applied an organ donation sticker to their driver's license. However, 40% of this previously unwilling cohort made a subsequent commitment to donate following either intervention.[24] This suggests that simple and brief interventions such as use of written materials and/or brief verbal discussions in the ambulatory clinic can have a significant impact on willingness to donate. Our study provides some evidence that such an approach may also be effective among African Americans.

There are important limitations to this study. First, the response and cooperation rates were relatively low, potentially introducing bias. Study participation and cooperation rates of difficult-to-reach populations such as African Americans are often low for a variety of reasons, including distrust.[25-28] Our cooperation rates are similar to those in studies using similar methods.[3,29,30] In addition, telephone surveys are more difficult to perform with the public's increasing use of cellular phones, caller identification and voicemail as well as a growing unwillingness to speak with solicitors over the phone. We attempted to maximize our response and cooperation rates by sending a letter informing participants of the study prior to survey administration and offering the option of completing the survey over the web. We also called nonrespondents up to eight additional times to maximize response rates. Second, this cross-sectional survey design cannot prove a cause and effect between signing a living will and willingness to become an organ donor. However, future studies may be designed based on these results to examine the relationship further. Third, our methods may exclude individuals from the lowest socioeconomic groups that may not have phones or may not be identifiable through the databases that we searched. Therefore, our results may not be generalizable to these groups.

Our study focused on data obtained from African Americans and whites living in similar census blocks. Unlike the U.S. population, African Americans and whites in our cohort were similar in level of education obtained and employment status, suggesting a similar socioeconomic status. As a result, extrapolations to the general population may be limited, although our method has the advantage of controlling for education and employment status. In addition, our findings that race is associated with the presence of a living will[31-33] and willingness to donate organs have been reported by others, as well.[3,4]

In summary, this study demonstrates that among the general population, speaking with a physician is associated with signing a living will and with willingness to become an organ donor. Furthermore, the presence of a living will is also an independent predictor of willingness to donate. Introduction of the topic of organ donation into discussions of advance care planning may represent an opportunity to increase organ donation among African Americans as well as whites. Given the importance of increasing organ donation, especially among African-Americans, future studies should examine the influence of advance care planning in the primary care setting as an opportunity to discuss organ donation and increase the availability of organs for donation.

Table 5. Predictors of willingness to donate

Predictor Variables	OR	(95% CI)
Ordinal Logistic Regression Model		
Female gender	0.74	(0.37–1.44)
African-American race (white=referent)	0.4	(0.2–0.81)
Presence of a living will	2.43	(1.13–5.23)
Having discussed organ donation with a physician	3.04	(1.07–8.67)
Willingness to receive a transplant if necessary	8.65	(2.80–26.7)
Logistic Regression Model		
Female gender	1.03	(0.47–2.24)
African-American race (white=referent)	0.29	(0.13–0.62)
Presence of a living will	2.92	(1.27–6.71)
Having discussed organ donation with a physician	3.96	(1.29–12.2)
Willingness to receive a transplant if necessary	5.90	(1.57–22.1)

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